

## Duchenne Muscular Dystrophy Pre-Clinic Dinner

On Thursday 22nd August 2013 MDNSW, in partnership with Northcott, hosted the third annual DMD Pre-Clinic Dinner in Wagga Wagga which was attended by 22 people. The event is a wonderful opportunity for families living with DMD to be able to meet and connect with other families who are facing similar challenges. It is a chance to build informal support networks, get to know the people who are supporting them in the services they are using and to just have a great night out as a family. We look forward to seeing everyone again at the event next year, along with some new faces too. Please contact Kejanna at [kejanna.taylor-king@mdnsw.org.au](mailto:kejanna.taylor-king@mdnsw.org.au) for more information.



## Illawarra Carer Support Group Pizza and Boccia Night



At the end of June we had a pizza night at Port Kembla Surf Club for the regular Boccia session which MDNSW sponsored. There was a great view, great company, great food and a great competition. There were a few new players so the experienced regulars kindly coached and encouraged the new players which made us all feel welcome. After warm ups and fun skill development activities we had a playoff between teams. We all had lots of fun, got to meet other families and found out more about the opportunities offered through Boccia. Mecenzi was great to watch and she is representing Australia in the Asia Oceania Games in October. We wish her the best of luck!

**Jill Coleman**, Illawarra Support Group member

## Blokes out Bush [BOB]



I have been going to Blokes out Bush for around two years. It is out in Narrandera NSW and I am driven out there by a carer. I was informed about the group by my case manager. BOB is a great place to talk to others who have MD. We often talk about how we are going with our daily lives. There is an amazing lunch provided and it helps that we all have a lot to talk about.

**Fred Smith**, BOB member

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## What a Camp – thanks ADHC!

Wow - what a camp this was! Lots of new campers and plenty of ol' timers met up with a bunch of the best carers and had the most brilliant time ever! Carers got slimed, Scott had the X-Factor, the young ones loved the Go-Karting and everyone got into Laser Skirmish, Orienteering, Great Race and the Radio Car Racing. The Hippy Shake party night absolutely went off with a bang, however I think the best part was how all the campers got on so well with each other and how many new friendships were formed. I think our amazing carers played a huge role in helping to make this happen so a big thanks to them and also to staff from the Neuromuscular Clinics for the best camp on record!

**Loretta Downie**, Manager Events and Client Programs



Charlie went hippy



Bo, Tex and Sarah get ready to party



Chef Ashton



Groovy Scott!



Clare and Kevin had a hoot



Chris and the slime man



Jenna rests up with Tash



Party night went off yet again

“ It is such a unique opportunity for these boys to feel they are part of a group - let their hair down, be themselves and have fun together with other kids in the exact same situation as them.  
*Lilian Wales, seasoned camper's mum* ”





# Camp Kula N' Gadu 2013



MD Staff groove to the Gangnam



Cory hit plenty of runs



Slime time Demi and Jonathan!



First time camper Mitchell and his team won a medal in Who Dunnit



Jamieson and Emma teamed up for Skirmish

“

This was my first camp and it was one of the best experiences I have ever had. The activities blew my mind! They were fun and challenging and that made them great. The carers were all so nice and I wish they could come back next year. I made some really good friends. It was cool to meet people who were like me. I felt kind of normal for the first time in ages. I think everyone who can go to camp, should. I can't wait till the next one! Thanks Loretta for letting me come.

*Jack Bailey, 8yrs, first time camper*

”



The Big Red Riders popped in for a visit



Tom lasered heaps of campers



Orienteering was a huge hit with everyone



Karaoke Kings



The Go Karts were no match for Kieren



Survivor Olympics was even trickier this year



Jack and Philip got hitched



# upcoming events

## Great **Boccia Bash** Sun 24 Nov

### CPA, Allambie Heights

The time has come for MDNSW players to take on the might of the players of CPA for our first ever Botchoff!! MD v CP – it should be a cracker of a tournament!!



## Sydney Metro Christmas Party

CBA Function Centre, Parramatta

Sun 8 Dec



Fri 7 – Sun 9 Feb, 2014

## Ngundabaa Mums' Weekend Retreat

A unique opportunity for Mums of children with MD to take time out for themselves for a relaxing weekend away in the beautiful Shoalhaven Lodge, Longreach.



## Blokes in a Boat Tuross Head

Fri 14 – Sun 16 Mar, 2014

Spend the weekend fishing and relaxing on the far south coast in its beautiful estuaries with other blokes who live with someone who has MD



## Adventure Camp 2014

### Port Stephens

Sat 12 – Wed 16 April

A camp for those with more mobility where everyone has an adventure of a lifetime!



## Byron Bay Couples' Retreat

Fri 16 – Sun 18 May, 2014

### Couples' Retreat

Get away for the weekend with your partner and experience all the beautiful atmosphere Byron Bay has to offer.



Taking **RSVPs** now!

*See website for details*

*...and coming soon  
an MD Theatre Retreat at Star City!*

# The Great Boccia Bash

*Our first MD v CP grudge match!*

Although Boccia was originally set up for those with cerebral palsy, the success of our MDNSW players of late has shown that we have what it takes to go all the way with this sport too. Whether you're a thrower or a ramper, or you've never played before or you're just learning the sport, come be a part of a fun, social day where MDNSW takes on CPA in what we hope will be an annual grudge match. We need as many players as possible so come and give it a go!!

*Anyone of any age or ability can play Boccia!*



Sun 24 Nov, 2013  
11.00am - 3.30pm

CPA Sports Hall  
187 Allambie Rd,  
Allambie Heights

*Free BBQ  
lunch provided*

Accommodation assistance available for a limited number of regional MDNSW players

# RSVP

Before Tue 19 Nov, 2013 to [loretta.downie@mdnsw.org.au](mailto:loretta.downie@mdnsw.org.au)  
or phone Jenny on 9809 2111 (option 3).

# FREE



## Come Spa With Me

Tired or stressed? Rest, Relax and Rejuvenate with the ladies in the Far North Coast at this magnificent Day Spa.

### Angourie Rainforest Resort

166 Angourie Road, Yamba

Sat 26 Oct, 2013  
9.00am to 4.00pm  
\$30.00 pp



## Melbourne Cup Swansea Style

Come and join us for a fabulous race day and enjoy a delicious 2 course meal and a complementary glass of bubbly.

### Swansea RSL Club

Chalmers Function Room, 5 Bridge St, Swansea

Tue 5 Nov, 2013  
11.30am - 3.30pm  
\$20.00 pp



## Christmas Light Spectacular

Enjoy a two course festive roast dinner before wandering through Australia's largest Christmas lights display.

### The Garden Terrace Restaurant

Hunter Valley Gardens



Sun 1 Dec, 2013  
6.30pm to 10.00pm

## Illawarra Brunch by the Beach

Celebrate Christmas with us for a delicious breakfast and enjoy the beautiful view of Kiama's harbour.

### Harbourside Brighton

Sat 9 Nov, 2013  
10.30am to 1.30pm



## The Big Orange Barbie

It's all happening again, last year's Christmas party was so successful we are inviting you and your family to join us again. A scrumptious barbequed Christmas roast, dessert and fun for the whole family.

### Orange Ex-Services Club



Sun 15 Dec, 2013  
12.00pm to 3.00pm

## Jingle in the Jungle Christmas Party

Sun 10 Nov, 2013  
12.00pm to 3.00pm



Share a beautiful Christmas lunch at this exotic and multi award winning resort, nestled beside 600 hectares of open rain forest.

### Angourie Rainforest Resort

166 Angourie Rd, Yamba

See details on our website



## National Disability Insurance Agency

### Experiences of our members with The National Disability Insurance Scheme

I was fortunate to live in the Hunter launch area for DisabilityCare Australia (now NDIA) and fitted the criteria. I registered online and was then contacted by my assigned Case Planner, Louise, just over two months ago. She then met me in my home and we discussed my needs and future goals and put a plan in place to achieve them. I was given the information that I needed to help arrange the supports and guidelines about managing these myself. The NDIA has a list of providers that are registered with them and I am able to choose the services from there. At the moment I am getting help with cleaning 2 hours a week and 2 hours of massage/ stretches a month. I cannot speak more highly of them.

***“NDIA makes direct payments into my bank account fortnightly and then I pay the provider for this service.”***



Lisa and Marcus Brown

It is a bit of a learning curve for all involved at the moment but I do feel motivated again which has triggered many positive thoughts for maintaining my strength and balance to keep walking. So for

anyone in the Newcastle area who is thinking they need support, I recommend you give them a call!

**Lisa Brown**, Hunter member

I read the advertisement for DisabilityCare Australia in my Community Newspaper, after which I called them to find out that I was eligible to access the program. An access appointment with DisabilityCare Australia was scheduled with a support officer at my home which made things a lot easier. In a short period of two times I was accepted to access DisabilityCare Australia and an appointment with a planner was made to prepare my Plan to reach my goals. My disability goals are to get out into the community more, to access regular physical activity, and to be

able to go out without help. My Plan was implemented and the activities that they funded are hydrotherapy/physiotherapy treatment, assistance with home cleaning, assistance with purchase of personal aids and of an electric powered wheelchair under advice from an occupational therapist.

***One phone call can change your life and has really made my future independence achievable.***

**Anne Rennie**, Hunter member

## Advokit-NDIS

Whether you are a person with a disability, a family member or an independent disability advocacy agency this website is for you. Advokit-NDIS is a website that aims to support advocacy for people with disabilities in connection with the National Disability Insurance Scheme. It aims to inform you about the rights and entitlements of people with disabilities under the NDIS and about how to engage with them in order to achieve supports that suit the wishes and circumstances of the

a person with a disability. It is created to empower you to be able to make the right choices using the new scheme's funds. It provides details on how to plan for supports and services, how to choose supports and services, how to manage those supports and services, explains the actual legislation and other instruments and allows you to become a participant of Advokit. In order to become a participant you need to fulfil the access criteria and navigate the process of making an access request. Once you



have become a participant the agency will provide support and assistance (including financial assistance) in relation to activities or meeting obligations for the NDIS. The Agency may provide general support for people with disabilities who are not participants, including coordination, strategic planning and referral services. To have a further look into Advokit or to become a participant visit

**[www.advokit.org.au](http://www.advokit.org.au)**

# If you have high support needs, have you enquired about **Attendant Care Packages?**

One of the most important things in my life is independent living in my very own home in the community and I am proud to say that I have lived happily in the community for 20 years now. When I was 19 I was living at home with my parents and sister, and had started my Social Work course at the University of Western Sydney. I was young and in love and wanted to get out and start a life of my own (AKA shack up with my fella!). So I applied for the Attendant Care Package through ADHC as we knew that we needed a more individualised form of support, and wanted to have a real say in our care. Attendant Care was designed for people like us who know what we need and have the skills to make our supports work for us.

The tips when applying for funding include:

- Have the support of a social worker or ask MDNSW for assistance in putting your application together – in fact ADHC prefer you to have a contact person
- Get letters of support from family, your employer, medical professionals, OT/physios and service providers
- During the application and assessment process think about all the aspects of your care needs and specifying everything, including when you are ill etc

## What is Attendant Care?

The Attendant Care Program (ACP) provides portable, flexible and individualised support for people with a physical disability and/or who need personal help to complete activities of daily living. Support covered includes personal care and domestic assistance.

## Who is eligible?

You may be eligible for an ACP package if you are:

- between 16 and 65 years old
- living in your own home, family home or in leased accommodation where you are managing the lease (people living and intending to continue living in supported accommodation such as group homes or residential care facilities are not eligible)
- able to live in the community with a capped number (usually up to 35) of personal assistance service hours per week and access community support
- ineligible for, or unlikely to be a priority for other ADHC provided or funded accommodation services in the short to medium term.

An ACP package is a suitable option for people with:

- a physical disability – including neuromuscular conditions - whose needs can be met with personal care support and who can be involved in managing their care; or
- a neurological degenerative condition including rapidly degenerative condition: or
- ventilation dependency (over 24 hours) in which case the package may be jointly funded and managed with NSW Health.

Being eligible does not guarantee you will receive a service. Places are limited and priority is based on need.



Carolyn's team of carers

**How do I apply?** To apply, you need to complete the Attendant Care Program and High Needs Pool application form (PDF), found on the ADHC website. Applications are accepted directly by Attendant Care. An application register is maintained when there are more eligible applicants than places.

**Choosing a service provider** - Once you have been approved for an ACP package, you need to choose a funding model and a service provider (unless you choose the Direct Funding model). The ACP service provider list provides a list of approved service providers by Local Planning Area. An Attendant Care package can operate under three different funding models, which determine the level of involvement the person with disability has in managing and administering their care:

**Employer Model** - Funds are paid to an approved service provider who employs the attendant carers and is accountable to ADHC for expenditure and service quality. Clients can be involved in the selection, rostering and management of attendant carers to different degrees.

**Cooperative Model** - Funds are paid to an approved service provider who manages the funds, provides administrative support and is accountable to ADHC for expenditure and service quality. Clients can employ their attendant carers and are responsible for managing their services.

**Direct Funding Model** - Funds are paid directly to the client who is responsible for employing their own care workers or purchasing approved services and managing their care. Clients take on the full employer/service provider responsibility and are accountable to ADHC for expenditure and service quality under a Funding Agreement. Under the direct employment option, the person with disability agrees to take on employer responsibilities and comply with all applicable legislation.

For more information go to [www.adhc.nsw.gov.au/individuals/support/everyday\\_living\\_support/attendant\\_care\\_program](http://www.adhc.nsw.gov.au/individuals/support/everyday_living_support/attendant_care_program)

## Carolyn Campbell-McLean

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**Ricky Camilleri**, MDNSW member

Enquire with MDNSW about how Little Heroes Care can assist with funding this device if you are under 25 years

## Old Ski Trip

Our family lives in Jindabyne in the Snowy Mountains of NSW and being so close to the NSW ski fields we all love snowsports. We have three sons Max 12, Samson 11 and Thomas 8. Max and Samson both have Duchenne Muscular Dystrophy. Having DMD has not gotten in the way of both boys being able to get on the hill with their brother Thomas as they can sit-ski. The boys and their Dad - Steven, Mum - Kylee and family friend Dave are members of Disabled Wintersport Australia (DWA). This fantastic organisation is run by volunteers who, with adaptive equipment, enable people with disabilities to get onto the snow and give them the experience of skiing. Steven, Kylee and Dave have been trained to use the sit ski and as a family can enjoy skiing together. Jindabyne Central School, which all the boys attend, has a Snowsports Program where both Max and Samson are able to participate just like their peers due to having access to sit-skis through DWA. We really want our boys to have the most "normal" fun life as they possibly can.

***"It's nice to see them enjoying something their mates do, that even with DMD, they can do too."***



Samson and Max skiing

Living in Jindabyne, our kids have an amazing time during both winter with skiing and summer with boating and quad biking. The DWA is available to anyone with any disability. For information on how you could take advantage of this wonderful organisation visit [www.disabledwintersport.com.au](http://www.disabledwintersport.com.au). Maybe your next trip could be to the snow and I am sure both boys would be more than happy to show you the ropes.

**The Old Family**, MDNSW members